



# International 100K Cohort Consortium

## MEETING SUMMARY

Virtual Summit  
Zoom

May 4-5, 2020

Hosted by the [Global Genomic Medicine Collaborative \(G2MC\)](https://ihccglobal.org)  
[ihccglobal.org](https://ihccglobal.org)

### **Vision for success:**

TO CREATE A GLOBAL NETWORK FOR TRANSLATIONAL RESEARCH THAT UTILIZES  
LARGE COHORTS TO ENHANCE THE UNDERSTANDING OF THE BIOLOGICAL AND GENETIC  
BASIS OF DISEASE AND IMPROVE CLINICAL CARE AND POPULATION HEALTH

## IHCC Third International Cohorts Virtual Summit Executive Summary

In 2015, the National Institutes of Health (NIH) launched an effort to identify all large-scale prospective cohort studies involving at least 100,000 participants to explore the potential of bringing them together to address scientific questions none could answer alone. This effort led to the commission of the Global Genomic Medicine Collaborative (G2MC) to bring together these cohorts through the International HundredK+ Cohort Consortium (IHCC). This group gathered for the First International Cohort Summit in the USA in 2018 followed by a Second Summit in Iceland in 2019. During planning of the Third Summit to take place in Santiago, Chile, the global outbreak of COVID-19 required a transition to virtual meeting format. Approximately 160 attendees from more than 23 countries attended the virtual Summit. The event in Santiago, Chile will be postponed to a date to be determined when attendee health and safety will not be at heightened risk due to COVID-19.

The virtual meeting objectives included:

- To galvanize the IHCC around a visionary charter and path forward (defining the IHCC organization, mission, membership, partnership opportunities, industry engagement).
- To examine how IHCC can rapidly mobilize worldwide cohorts to address the COVID-19 pandemic.
- To introduce the IHCC to a Cohort Data Atlas that can be used to stimulate and enable collaborations among cohorts.
- To engage the entirety of the IHCC membership in developing the key topics to chart a scientific agenda that can only be achieved by assembling cohorts and their data.

The Summit included keynote presentations from Francis Collins (National Institutes of Health (NIH), USA), Soumya Swaminathan (World Health Organization (WHO), Switzerland), and Jeremy Farrar (Wellcome Trust (WT), UK) along with the following sessions:

- Session 1 – IHCC Work Team Progress – Governance
- Session 2 – IHCC Work Team Progress – Science and Technology
- Session 3 – Scientific Presentations across each Work Stream
- Session 4 – External Engagement (Other Consortia and Industry Partners)

In Session 1, attendees learned details of the IHCC Charter outlining governance, membership, and expectations for participation. IHCC Policies on publications, collaborations with industry, and data sharing were also presented for review by membership. Discussion among attendees and presenters illustrated support for the Charter and Policies. These will be ratified following the Summit.

Session 2 included a live demonstration of the IHCC Cohort Data Atlas prototype, enabling cohort discovery of cohort variables, specimens, and populations of interest. User testing of the Atlas will continue in the coming months as additional cohort data is mapped and uploaded to the browser. The Scientific Strategy Team presented preliminary results of an IHCC cross-cohort pilot project on polygenic risk scores for four selected traits. A publication is in progress to highlight the proof of principle for the cross-cohort analysis as well as the Polygenic Risk Score (PRS) prediction results. Three to five additional pilot projects will be initiated on a 12-18-month timeline with funding support from the NIH and the WT.

In Session 3, presenters shared scientific progress across a variety of domains including data infrastructure, equity in polygenic risk scores, standardized phenotype measures, precision medicine initiatives, and principles and codes of conduct for collaboration.

Session 4 highlighted opportunities for collaboration through the Davos Alzheimer’s Collaborative (DAC), Global Alliance for Genomics and Health (GA4GH), International Common Disease Alliance (ICDA), Global Biodata Coalition (GBC), and Global Genomic Medicine Collaborative (G2MC), and industry partners such as Regeneron, GlaxoSmithKline (GSK), and Illumina.

In recognition of the current global research priorities, IHCC is collectively launching several COVID-19 response initiatives. Presenters shared current research on COVID-19 surveillance, sex and age disparities, mental health, and host response variants. Several Scientific Working Groups (SWGs) will be established to examine the global expansion of COVID-19, the impact of mental health and environmental exposures on COVID-19, and biospecimen standards development.

Discussion during the Summit led to several key actions in accordance with the meeting objectives:

**Objective One:**

*To galvanize the IHCC around a visionary charter and path forward (defining the IHCC organization, mission, membership, partnership opportunities, industry engagement).*

**Key Actions/Next Steps:**

- Provide additional feedback on IHCC Charter as needed. A formal ratification process will follow in June 2020.
- Provide responses to the [data sharing survey](#) by June 5, 2020 to inform the IHCC Core Data Sharing Principles.
- Provide additional comments on policy documents as needed by May 22, 2020 to Laura Lyman Rodriguez. Final versions will be approved by the SSC and distributed to membership.
- IHCC members interested in joining the working groups (Policy and Biodata Sharing, Data and Infrastructure, or Scientific Strategy) are encouraged to contact the Team leads or IHCC Secretariat.

**Objective Two:**

*To examine how IHCC can rapidly mobilize worldwide cohorts to address the COVID-19 pandemic.*

- Provide responses to the IHCC COVID-19 cohort survey if not already complete (will be recirculated via email to cohorts).
- Indicate interest in joining any of the COVID-19 SWGs by May 12, 2020. Contact Eric Plummer to join.
- Cohorts measuring the impact of protective mental health interventions for COVID-19 are encouraged to contact Wellcome Trust (Jordan Smoller, Andre Brunoni, Sarah Bauermeister).
- For COVID-19 research studies, register on the ICDA COVID-19 Host Genetics Initiative.

**Objective Three:**

*To introduce the IHCC to a Cohort Data Atlas that can be used to stimulate and enable collaborations among cohorts.*

- Cohorts may continue to provide data dictionaries for IHCC Cohort Data Atlas development to [ihcc-browser@googlegroups.com](mailto:ihcc-browser@googlegroups.com). IHCC cohort data will be further populated in the atlas. Members are encouraged to provide feedback to Data and Infrastructure Team on use cases for atlas queries. This Team will establish a compelling set of research and clinical showcase applications. COVID-19 phenotyping will be added to the Atlas. Cohorts interested in cross-cohort COVID-19 research may also consider providing data dictionaries for harmonization and cohort discovery.
- An IHCC Resource Center with relevant data tools and other cohort resources will be created and shared on the IHCC website.



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**Objective Four:**

*To engage the entirety of the IHCC membership in developing the key topics to chart a scientific agenda that can only be achieved by assembling cohorts and their data.*

- IHCC will collectively develop a five-year roadmap.
- To join the Davos Alzheimer's Collaborative, contact Drew Holzapfel and/or attend the scheduled calls on May 19/20, 2020.
- Scientific Strategies team will launch three to five scientific initiatives with a 12-18-month timeframe using a federated approach with an emphasis on global diversity more than -omics.
- Collaborate on the COVID-19 specific activities (see Objective Two)
- Continue to develop a shared scientific agenda through implementation of the Charter with new governance structure (elected members of the Steering Committee, etc.) and virtual working group meeting in ~six months.

## Abbreviations

ACTIV	Accelerating COVID-19 Therapeutic Interventions and Vaccines
AD	Alzheimer's Disease
AUC	Area under the curve
BMI	Body mass index
COVID-19	Coronavirus Disease
DAC	Davos Alzheimer's Collaborative
dbGaP	Database of Genotypes and Phenotypes
EC	Executive Committee
EHR	Electronic Health Record
ELISA	Enzyme linked Immunosorbent Assay
G2MC	Global Genomic Medicine Collaborative
GA4GH	Global Alliance for Genomics and Health
GBC	Global Biodata Coalition
GDPR	General Data Protection Regulation
GIS	Geographic Information System
GSK	GlaxoSmithKline
GWAS	Genome-Wide Association Study
HFSP	Human Frontier Science Program
HL7	Health Level Seven International
ICDA	International Common Disease Alliance
ICGC	International Cancer Genomes Consortium
ICS	International Cohorts Summit
IHCC	International HundredK+ Cohorts Consortium
ISO	International Organization for Standards
LMIC	Low- and/or Middle-Income Country
LoF	Loss-of-Function
LPS	Longitudinal Population Study
MAMA	Multi-Ancestry Meta-Analysis
MERS	Middle East Respiratory Syndrome
NIH	National Institutes of Health (USA)
NIMH	National Institute of Mental Health (USA)
PM	Precision Medicine
PRS	Polygenic Risk Score
PVI	Pandemic Vulnerability Index
RCT	Randomized Control Trial
SSC	Scientific Steering Committee
SARS	Severe Acute Respiratory Syndrome
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SNOMED	Systematized Nomenclatures of Medicine
SWG	Scientific Working Group
T2D	Type 2 Diabetes
WEF	World Economic Forum
WGS	Whole genome sequencing
WT	Wellcome Trust